

**DRAFT for February 25<sup>th</sup> GTF Meeting**  
**Genetic Information Protection Matrix for Washington State**

**Section I**

	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Encompasses Genetic Information</b>	<u>Yes</u> , health information is defined very broadly and is generally interpreted to include genetic information.	<u>Yes</u> , to the extent that the definition of health care information is interpreted to include genetic information.	<u>Yes</u> , to the extent that the definition of health care information in UHCIA is interpreted to include genetic information.	<u>Yes</u> , it protects all readily identifiable information.
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Protects Genetic Information from Unauthorized Release to Third Parties</b>	<u>Yes</u> , requires patients' consent for the release of any health information. Blanket consent is acceptable for the release of health information for treatment, health care operations, and payment. Specific consent is required for all other releases. Exceptions exist for public health, research, law enforcement, and other uses required by law.	<u>Yes</u> , if the definition of health care information is interpreted to include genetic information. Patient consent is required for the disclosure of health care information.	<u>Yes</u> , if the definition of health care information is interpreted to include genetic information. Patient consent is required for the disclosure of health care information.	<u>Yes</u> , it prevents state agencies, employees and contractors from selling or disclosing information.
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Protects Stored Biological Samples</b>	<u>No</u> , defines health information as oral, written or electronic; does not imply or specify biological samples.	<u>No</u> , does not explicitly refer to biological samples.	<u>No</u> , does not explicitly refer to biological samples.	<u>No</u> .

	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Regulates <u>Use</u> of Genetic Information by Health Insurance Companies</b>	<u>Yes</u> , the portability component explicitly states that genetic information may not be considered a pre-existing condition unless a patient has a corresponding diagnosis. It also provides that insurers cannot use genetic information to apply different eligibility requirements or rates to individuals within a group plan. Health insurers are subject to the same privacy requirements as health care providers and facilities. <u>No</u> , it does not regulate what information an insurance company may ask for from an individual.	<u>No</u> , it does not generally apply to insurers. (70.02.045 does prohibit third party payors from releasing health care information)	<u>Yes</u> , it makes insurers subject to the provisions of the UHCIA in regards to disclosure and protection of health care information, although exemptions are broader with respect to insurers activity. <u>No</u> , it does not regulate how the insurer can use the information in practice.	<u>No</u> , only applies to state governments agencies, employees and contractors.
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Regulates <u>Use</u> of Genetic Information by Life Insurance Companies</b>	<u>No</u> .	<u>No</u> .	<u>No</u> , it only applies to health insurance.	<u>No</u> , only applies to state governments agencies, employees and contractors.
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Regulates <u>Use</u> of Genetic Information by Other Entities (e.g. banks, housing, schools)</b>	<u>No</u> , does not apply to genetic information outside of the health care system.	<u>No</u> .	<u>No</u> , it only applies to health insurance.	<u>No</u> , only applies to state governments agencies, employees and contractors.

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<b>Regulates Use of Genetic Information by Employers</b>	(?) <u>Yes</u> , insofar as an employer cannot deny an employee health care benefits offered to other employees based on genetic information. <u>No</u> , it does not regulate use of genetic information for employment decisions.	<u>No</u> .	<u>No</u> , it does not regulate use of genetic information for employment decisions.	<u>Yes</u> , it regulates the collection and release of readily identifiable information if the employer is a state agency or contractor
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Protects People with a Genetic Susceptibility (Asymptomatic)</b>	<u>Yes</u> , individuals with a record of a genetic susceptibility are protected from the disclosure of that information. <u>Yes</u> , from insurance discrimination as described above. <u>No</u> , it does not protect from employment or other discrimination.	<u>Yes</u> , insofar as health care information is interpreted it include genetic information, individuals with a record of a genetic susceptibility are protected from the disclosure of that information. <u>No</u> , it does not protect against employment or other discrimination.	<u>No</u> , it does not regulate health insurance eligibility requirements, however it mandates that those requirements are disclosed prior to enrollment. (pre-existing conditions are defined and regulated elsewhere)	<u>Yes</u> , it limits "the collection of personal information to that reasonably necessary for purposes of program implementation, authentication of identity, security, and other legally appropriate agency operations.
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Protects People with a Symptomatic Genetic Disease</b>	<u>Yes</u> , insofar as health care information is interpreted it include genetic information, individuals with a record of a genetic susceptibility are protected from the disclosure of that information. <u>No</u> , it does not protect against employment or other discrimination. <u>Yes</u> , from health insurance discrimination as described above. <u>No</u> , it does not protect from employment or other discrimination.	<u>Yes</u> , insofar as health care information is interpreted it include genetic information, individuals with a record of a genetic susceptibility are protected from the disclosure of that information. <u>No</u> , it does not protect against employment or other discrimination.	<u>No</u> , it does not regulate health insurance eligibility requirements, however it mandates that those requirements are disclosed prior to enrollment. (pre-existing conditions are defined and regulated elsewhere)	<u>Yes</u> , it limits "the collection of personal information to that reasonably necessary for purposes of program implementation, authentication of identity, security, and other legally appropriate agency operations.

	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Protects Genetic Information from Disclosure to Agencies Outside of the Health Care System</b>	<u>Yes</u> , requires specific consent for disclosure but it does not protect the information once it leaves the health care system.	<u>Yes</u> , requires specific consent for disclosure but it does not protect the information once it leaves the health care system.	<u>Yes</u> , it requires specific consent for disclosure of health information.	Yes, it prevents state agencies, employees or contractors from disclosing personal information to any party.
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Includes Specific Informed Consent Requirements</b>	<u>Yes</u> .	<u>Yes</u> .	<u>Yes</u> . It mandates the same consent requirements as UHCIA	<u>No</u> .
	<b>Health Information Portability and Accountability Act (HIPAA)</b>	<b>Washington State Uniform Health Care Information Act (UHCIA)</b>	<b>Patient's Bill of Rights SB 6199</b>	<b>Governor's Executive Order on Privacy</b>
<b>Includes Exceptions for Research</b>	<u>Yes</u> .	<u>Yes</u> .	?	?

## Section II

	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Encompasses Genetic Information</b>	<u>Yes</u> , protects all information used for research purposes. In addition researchers can apply for a federal certificate of confidentiality.	<u>Yes</u> , the EEOC interprets the ADA "regarded as" clause to encompass existing and pre-symptomatic genetic disorders.	<u>Yes</u> , WAC 284-43-720 limits the use of genetic information for determining a pre-existing condition.	<u>Yes</u> , disability is broadly defined and is interpreted to include genetic disorders.
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Protects Genetic Information from Unauthorized Release to Third Parties</b>	<u>Yes</u> , prevents researchers from disclosing information about subjects except as required by law.	<u>No</u> , does not regulate the release of information.	<u>Yes</u> , requires insurers to protect patients' privacy according to existing state and federal laws.	<u>No</u> .
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Protects Stored Biological Samples</b>	<u>Yes</u> , considers use of biological samples as research using human subjects.	<u>No</u> .	<u>No</u> .	<u>No</u> .
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Regulates Use of Genetic Information by Health Insurance Companies</b>	<u>No</u> .	<u>No</u> .	<u>Yes</u> , insofar as defining a pre-existing condition is concerned and insofar as the rules disallow "high-risk" rate setting by health insurance carriers.	<u>Yes</u> , addresses issues related to discrimination based on status in a protected class (e.g. disabled)

	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Regulates <u>Use</u> of Genetic Information by Life Insurance Companies</b>	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>Yes.</u> , addresses issues related to discrimination based on status in a protected class (e.g. disabled)
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Regulates <u>Use</u> of Genetic Information by Other Entities (e.g. banks, housing)</b>	<u>No.</u>	<u>No.</u>	<u>No.</u>	<u>Yes.</u> , addresses issues related to discrimination based on status in a protected class (e.g. disabled)
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Regulates <u>Use</u> of Genetic Information by Employers</b>	<u>No.</u>	<u>Yes.</u> , employers are required to make reasonable accommodations for person with disabilities and they are disallowed from requiring medical/genetic testing that is not consistent with business necessity.	<u>No.</u>	<u>Yes.</u> , addresses issues related to discrimination based on status in a protected class (e.g. disabled)
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Protects People with a Genetic Susceptibility (Asymptomatic)</b>	<u>Yes.</u> , if the information was obtained under a research protocol.	<u>Yes.</u> , the EEOC interprets the "regarded as" clause to be protective of persons with pre-symptomatic genetic conditions.	<u>Yes.</u> , by limiting the use of genetic information without a diagnosis in the determination of a pre-existing condition.	<u>Yes.</u> , definition of disability includes conditions that are perceived to exist whether or not they exist in fact.
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Protects People with a Symptomatic Genetic Disease</b>	<u>Yes.</u> , if the information was obtained under a research protocol.	<u>Yes.</u> , an individual with a disability under the ADA is "a person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, or is regarded as having such an impairment. Major life activities are activities that an average person can perform with little or no difficulty such as walking, breathing, seeing, hearing, speaking, learning, and working."	<u>Yes.</u> , to the extent that the disease is not classifiable as a pre-existing condition.	<u>Yes.</u> , definition of disability includes conditions that are perceived to exist whether or not they exist in fact.

	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Protects Genetic Information from Disclosure to Agencies Outside of the Health Care System</b>	<u>Yes</u> , protects information obtained in research from disclosure to all entities except when required by law.	No, does not regulate disclosure of information.	<u>Yes</u> , requires insurers to protect patients' privacy according to existing state and federal laws.	<u>No</u> .
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Includes Specific Informed Consent Requirements</b>	<u>Yes</u> .	?	?	<u>No</u> .
	<b>Institutional Review Board Oversight</b>	<b>American's with Disabilities Act</b>	<b>Office of Insurance Commissioner Rules</b>	<b>Human Rights Commission Statute</b>
<b>Includes Exceptions for Research</b>	<u>Yes</u> , some research may be exempt from IRB review. For example, privately funded research is not subject to federal rules and guidelines. Also, some federally funded research may be exempt if it meets specific requirements.	No.	?	<u>No</u> .